Patients’ understanding of risk: a qualitative study of decision-making about the menopause and hormone replacement therapy in general practice

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**Objective.** To explore women’s understanding of the risks associated with the menopause and hormone replacement therapy (HRT).

**Methods.** Two general practices in Cambridge participated in this qualitative study using focus groups and semi-structured interviews. Forty women aged between 50 and 55 years, known to be current users, ex-users, or never-users of HRT were included in the study.

**Results.** Participants viewed risk as a danger: coping with risk required an assessment to facilitate an informed decision. To understand risk and make a personal interpretation, patients used their own knowledge, the presentation and context of that risk, together with their individual belief system particularly relating to representations of womanhood, lay beliefs and fatalism, control and choice. Experience, age and emotions often modified the salience of risk, and participants then used this meaning to weigh up the risks and benefits of a particular threat.

**Conclusion.** Participants gained understanding of risk by an active risk assessment process involving individual and complex interplay between knowledge and core beliefs, allowing the assessment of risks and benefits to facilitate an informed decision about the menopause and HRT.

**Keywords.** Decision-making, general practice, HRT, menopause, risk.

**Introduction**

Discussions about risk form a significant part of clinical discourse in primary care and Calman recently described the ‘unique opportunity’ that the management of risk presents for GPs. Examples of general practice topics where risk management is important include antenatal care, lifestyle changes such as smoking cessation, genetic risk identification and counselling, the appropriate use of medicines, and cancer screening. This management of risk comprises both accurate risk assessment and effective risk communication.

Accurate risk assessment by both patient and practitioner relies on the dissemination of accessible evidence-based information. It may be optimized by the use of tools such as computerized decision support software (CDSS), which already exists for the primary care risk assessment of coronary heart disease and family history of breast cancer. Effective risk communication is complex, and depends upon the meaning of risk to both the health professional and the patient. The 1995 ‘pill scare’, where the absolute and relative risk information about third generation oral contraceptive pills were misinterpreted by health professionals, patients and the media alike, illustrates the importance of understanding both the language of risk communication and the varying perceptions of risk information.

The ‘language of risk’ is fundamental to enable both doctor and patient to reach a shared and full understanding. A risk is usually described by health professionals as a single number, odds or probability of the occurrence of a negative outcome, and Calman suggests the need to clarify and standardize the language of risk to improve health professionals’ communication with patients. Several methods have been described, comprising both verbal and numerical elements. Primary care professionals have been shown to be sceptical about using a standard language to communicate with patients, although finding it potentially useful for communication between professionals. Furthermore, a standard language does
not give individual patients flexibility, and has different meanings for different people and in different situations.

Our current knowledge about risk perception in the clinical setting is equally uncertain. The literature suggests that both doctors’ and patients’ risk perceptions are influenced by the severity and consequences of the risk occurring, as well as by individual characteristics such as mood, a desire for control, previous experiences, and the personal belief system. The framing of risk information (different presentations of factually equivalent information) has also been shown to be an important influence on decision-making, but this extensive literature is mainly in an experimental setting, and there is evidence that framing variations may have different effects in clinical settings. A recent primary care study on the framing of risk information in hypertension showed that relative risk formats are much more persuasive for treatment compliance than absolute risk formats. Social science literature also suggests that lay beliefs about inheritance differ from the biomedical model, and this may also be the case with lay and professional understanding about risk issues.

To study the primary care patient’s understanding of risk, a common consultation topic involving decision-making in circumstances of uncertainty was chosen. Discussions about the menopause and hormone replacement therapy (HRT) occur frequently in general practice: in the UK 10–15% of women aged between 45 and 55 are prescribed HRT each year. These discussions involve uncertainty because there are different constructions of the menopause and inconclusive evidence about HRT: while the biomedical viewpoint regards the menopause as an illness/deficiency with a treatment/replacement available, the lay viewpoint differs and women generally view the menopause as a natural process, which does not require medication unless severe symptoms are present. Therefore, women’s decision-making processes surrounding HRT are complex.

This study uses risk discussions about the menopause and HRT to explore women’s understanding of risk issues. The aim is to inform our comprehension of the meaning of specific risks to the primary care patient, and thereby to enhance risk communication in the consultation.

Methods

This study used the qualitative methodologies of focus groups and interviews. Focus groups can give insight into the range of views on a particular topic, and to facilitate free discussion in a focus group the participants need to share a common interest in the topic while having enough diversity to provoke the exchange of ideas. The aim was therefore to organize the groups according to their HRT experiences. Subsequent interviews were used to explore individual views in more depth.

Patients were recruited from two Cambridge practices (Practice 1: list size 5500, Jarman Underprivileged Area Index (JUAI) J1 0.1%; Practice 2: list size 6700, JUAI J1 17.2%), where all women between the ages of 50 and 55 were identified and HRT usage established (Current-User, CU; Never-User, NU; or Ex-User, EU). The practice computers randomly selected 30 patients from each HRT-usage group, who were invited to participate in a focus group (after their GP had excluded all patients with psychological, psychiatric or chronic medical conditions which would make them unfit to participate in a focus group or interview).

The focus groups were organized in local settings away from surgeries, such as a church hall, and took place between March and May 2000. An experienced facilitator ran all groups, while the author FMW observed and made field notes with the participants’ knowledge and consent, in order to enhance understanding of the group dynamics and process. Women who were unable to attend a group but wished to participate, were offered a semi-structured interview in their own home.

The content of focus groups and interviews was similar. Initially, each participant completed a short questionnaire to provide socio-economic details. A risk game derived from Kitzinger followed, which aimed to develop a friendly atmosphere and familiarize participants with some of the key concepts. The game involved 16 laminated cards, each of which bore a single legend of a phrase or figure (see Table 1). The first four cards, from the ‘Words’ category, were placed in a random way on a central table. The group participants were told that the discussion process was of greater interest than the outcome, and then asked to turn over

<table>
<thead>
<tr>
<th>Category of card</th>
<th>Legend on card</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Presentation/ framing of risk)</td>
<td>(Size of risk)</td>
</tr>
<tr>
<td>Words</td>
<td>1 Moderately high</td>
</tr>
<tr>
<td></td>
<td>2 Moderate</td>
</tr>
<tr>
<td></td>
<td>3 Very low</td>
</tr>
<tr>
<td></td>
<td>4 Minimal</td>
</tr>
<tr>
<td>Numbers/odds</td>
<td>5 1:100</td>
</tr>
<tr>
<td></td>
<td>6 1:1000</td>
</tr>
<tr>
<td></td>
<td>7 1:100 000</td>
</tr>
<tr>
<td></td>
<td>8 1:1 000 000</td>
</tr>
<tr>
<td>Community scale</td>
<td>9 One person in a street</td>
</tr>
<tr>
<td></td>
<td>10 One person in a village</td>
</tr>
<tr>
<td></td>
<td>11 One person in a large town</td>
</tr>
<tr>
<td></td>
<td>12 One person in a city</td>
</tr>
<tr>
<td>Comparative mortality rates</td>
<td>13 Deaths in Britain per year from any cause</td>
</tr>
<tr>
<td></td>
<td>14 Deaths in Britain per year from any cause, age 40</td>
</tr>
<tr>
<td></td>
<td>15 Deaths in Britain per year from murder</td>
</tr>
<tr>
<td></td>
<td>16 Deaths in Britain per year from oral contraceptives</td>
</tr>
</tbody>
</table>
each subsequent card, and, after discussion with the group, place it on the chosen ‘Word’. The game lasted ten to fifteen minutes, and the majority of the participants found it interesting or stimulating, saying that it provoked ideas about ways of expressing risk, and proved a relaxing and often amusing way of meeting the other group members. A minority did not find the game either interesting or helpful: one called it a ‘waste of time’ and two found it difficult to play (both had a first language other than English).

The ensuing discussion lasted up to one hour and five broad questions were covered which had been developed from a literature review and discussions with colleagues, and which were slightly modified between groups in response to the preceding discussions. The facilitator used these questions to initiate the discussion, sometimes also using probes to elucidate participants’ ideas, redirect the discussion or summarize. This paper examines the discussions prompted by three of the questions (see Table 2).

All patient contacts were audio-taped, professionally transcribed in full, and subjected to ‘Framework’ analysis\(^{15}\) by the first author. The transcripts were read repeatedly, and an iterative process followed, involving the stages of familiarization with the data, identification of a thematic framework, and coding using ATLAS Ti software. The final stages of mapping and interpretation involved both authors. Research rigour was enhanced by giving attention to measures to improve reliability and validity.\(^{16}\) The quotations that follow were chosen to reflect a range of both consensual and dissenting views. Attempts have been made to give a fair representation of views from each HRT user group, and both practices.

**Results**

*Participants and group dynamics*

One hundred and seventy-eight women from both practices were approached by letter and 96 replied: further telephone recruitment to group and interview resulted in a final 40 participants (groups 36; interviews 4). Groups were convened until it was felt that there was saturation of data and no new ideas were emerging. It was not possible to stratify the groups as planned, with three groups for each practice (one each for Current-Users, Never-Users and Ex-Users). Instead, there was one group for Never-Users \((n = 6)\), two for Current-Users \((n = 8 \text{ and } 5)\), and three mixed groups intended mainly for Ex-Users \((n = 6, 6 \text{ and } 5)\), with two of the groups having patients from both practices. Socio-demographic data for each group of participants (including the interviewees) are shown in Table 3. Overall, the majority of these women were married (80%), and had children (90%), with approximately half working...
full-time and only 15% not employed. Over 80% of participants described themselves as in good or excellent health, and the majority were non-smokers (87.5%), alcohol-users (65%) and regular exercisers (53%). The group dynamics appeared to be influenced by personality, education level, and whether English was not a woman’s first language, rather than HRT usage or practice. There was a strong feeling of rapport, support and kindness to each other, which seemed to facilitate the development of ideas.

Participants’ understanding of risk
In general, the participants viewed risk as a danger, which required an assessment to enable an informed decision about how to cope with it. Personal interpretation of the meaning of a risk involved using their knowledge, the presentation and context of that risk, together with their unique belief system particularly relating to representations of womanhood, lay beliefs and fatalism, control and choice. Experience, age and emotions often modified the meaning of a risk, and participants then used this meaning to weigh up the risks and benefits of a particular threat.

Risk knowledge
Knowledge of risk was gathered from many sources, and influenced by the context and presentation of each risk issue:

Personal experience All groups discussed the comparative influences of ‘nature’ (from within themselves) and ‘nurture’ (from without). All talked about the importance of their family history, current symptoms and personal history. Many participants viewed their family history as unique and individual, providing not only a major source of risk knowledge, but also a sense of personal liability to developing certain disease:

“There’s only my mother, a younger brother and an older sister surviving out of 13 children, but all that side have died of cancer from the mouth to the tail end, so ... as far as I’m concerned, I’m on a reasonably high risk of getting it.” (D5–EU)

Current symptoms were also very influential, particularly the severity or seriousness of these symptoms. The concept of ‘suffering’ from symptoms appeared to be particularly important in risk appraisal:

“It’s got to be how you’re suffering. Say with HRT, if you have certain symptoms that you actually cannot cope with, when somebody says you’ve got an x chance of getting whatever [side-effect], you would actually think ‘I’m prepared to take that risk because if that’s the only way I can get rid of these feelings, I’m willing to take that risk’.” (F4–CU)

A personal history of illness, and life events such as bereavement or unemployment, were also salient. Most of the groups also discussed environmental risks such as smoking, diet and alcohol intake, and modes of transport. Several instances were given of the women’s own risk-taking (e.g. hitchhiking) or risk-aversion (e.g. stopping the oral contraceptive pill) behaviour in the past, in order to elucidate their sense of risk now. Information from the media, often providing ‘expert knowledge’, was felt by many to be central to the gathering of risk knowledge. However, it was often viewed with scepticism and some felt that expert opinion might vary, just as statistics were felt to vary or be open to manipulation:

“Experts are telling you this, that it’s good for you, then it’s not good and they change their minds.” (A2–NU)

Indeed, personal experience was often given more weight than expert opinion:

“I’ve come to the conclusion to ignore the statistics on other people and just go from my own experience.” (A5–NU)

Risk presentation and context. The participants felt that their comprehension of risk issues was affected by the way the risk information was presented. Most understood the size and framing of risks by using words and numbers, and these both needed range and ranking (put in order of magnitude) to give meaning. Words were translated into numbers and numbers were translated into words. Words needed numbers, but numbers did not necessarily need words: both needed contexts to give meaning and comprehension. While some felt more empathy with words, others felt more with numbers:

“Numbers don’t mean an awful lot to me, I’m a words person, I think.” (I4–NU)

Numbers were felt by some to be ‘abstract’, ‘scientific’ or ‘data’, and some people felt they were truthful, while others felt that statistics could be changeable, or even lie. Words were felt to be an opinion, which gave personal meaning and context: they could be comfortable, but could also be used as camouflage. Some felt that the opinion of others could take the risk judgement away from themselves when they wanted to make their own risk assessment, so this was generally viewed negatively:

“In order to get a correct perception, you’ve got to have both numbers and your verbal interpretation of what those numbers mean.” (F4–CU)

“I think by saying that it’s one in a million, you’re able to make up your own mind rather than someone having made it up for you, by saying ‘This is a minimal risk’.” (D2–CU)

“In other words you feel as if you’re trying to be talked into something.” (D3–CU)

Most women needed the context of risk information to make sense of something’s ‘riskiness’, and to gain
personal meaning and comprehension. The source of risk information, plus its proximity to personal experience, influenced the seriousness of that knowledge, and its emotional impact:

“I think it depends on how it affects you personally. If you hear of a teenage boy being stabbed, if you’ve got a teenage son, then it means much more doesn’t it?” (F2–CU)

Core beliefs
The participants demonstrated sophisticated personal belief systems, which were based on beliefs about illness and health and family history in general:

“We’ve swapped the measles, mumps and rubella for cancer and heart disease and bone disease, MS, Parkinson’s, all these new modern . . . How many people did you know who had MS in your granny’s days for instance?” (E1–CU)

There were also particular debates about the specific issues of womanhood, fatalism, control and choice:

Womanhood. The most salient beliefs surrounded events of womanhood such as antenatal screening and childbirth, and these often provided facts that were used as comparisons for other risks:

“[Before amniocentesis] we’d had a whole morning of medicos explaining to us that there was no risk or what the risk was, and giving us numbers and trying to verbalize it. When it’s happened to you, you then assess risk completely differently.” (F4–CU)

“I associate numbers with personal experiences. When I [heard] 1 in 100 I immediately thought of my twins. It’s a nice risk that I had twins, and I was just thinking that . . . I’ve hardly met anyone at all with twins, so you might think 1 in 100 sounds quite high, but in my general life, I have not met many of those other 1’s in 100.” (B6–CU)

The large majority of participants were mothers who saw their role of ‘carer’ as minimizing or avoiding hazards for their family, particularly to protect children. Risk for a family member was usually felt to be more hazardous than personal risk:

“You think a lot harder if you’re subjecting your children even to a very, very, very small risk, whether it’s worth it or not.” (B6–CU)

“You’ve got to work towards minimizing those risks, haven’t you?” (B3–CU)

Fatalism, control and choice. Superstition was mainly presented as fate or chance: while some women felt immune from risks, others felt more fatalistic. Most participants felt that there were some risks over which they had no control, such as a family history of a disease, or an accident, and these were viewed with a sense of inevitability:

“Sometimes things can get so doom laden. Everything you do has got a risk.” (B2–CU)

“Well, you can cross the road and it’s a risk. Everything you eat is a risk.” (B7–CU)

“You wouldn’t do anything, though, if you thought about it all the time . . .” (B5–CU)

Conversely, environmental risks such as smoking or flying could be chosen or controlled. Choices about controllable risks seemed to be based on the current effect rather than the future prevention, and most women needed to exercise some form of choice or control:

“Being knocked over by a bus is quite different to whether you decide to drink a lot or smoke a lot so there’s personal choice involved in it, and I don’t think you can quite view that in the same way as other risks.” (B7–CU)

Modifying factors. Risk issues were generally felt to be difficult to assimilate, and not necessarily beneficial or helpful: many participants felt that experience, age and emotions often modified this. Age and experience made some feel more vulnerable, perhaps due to more time and reflection, and many mentioned their own ability to take or ignore risks when younger:

“But don’t you think as you get older, you get more aware of risk? Your perception of risk becomes more acute?” (F4–CU)

“You feel more vulnerable, don’t you? . . . I think you’re more optimistic when you’re young, because you think anything’s possible . . .” (F2–CU)

“I think it’s increased knowledge and increased awareness makes you more averse to risk. So the more you know about something, the less willing you are to accept those risks associated with it, possibly.” (F4–CU)

Risk knowledge also produced a range of emotions, from denial or fear, through anxiety and confusion, to reassurance.

Weighing up risks and benefits
Participants talked about using their understanding of risk issues to weigh up the risks and benefits of a potential hazard, with the aim of making an informed choice:

“I guess she was kind of weighing it up and saying that she’d rather be a bit fatter than smoke at the moment.” (A4–NU)

“I think we just turn it into acceptable or not acceptable, really.” (B7–CU)
Many discussed their search for ‘unbiased’ ‘whole’ truth upon which to make their risk decisions:

“There is no such thing as risk, there is only certainty. You either die, you either live.” (D3–EC)

and many debated their need for individualized, tailor-made risk information:

“I would consider [information] that’s more tailored to the individual, instead of being given books that say ‘The risk is this, the risk is that.’ It’s too general. Why isn’t it tailored for the person who’s there? Instead it’s a blunderbuss approach really, it’s just kind of so wide.” (C2–NU)

Sometimes strategies were devised to minimize the risk, and often current thoughts about a risk were given greater weightiness than future prevention, or prevention of future complications. There was a spectrum of opinion as to whether knowledge about a risk altered behaviour. Although some felt it did, others felt that risky behaviour might continue despite the knowledge of inherent risks:

“I think [smoking is] risky, but then everything’s risky. Every day is risky—you don’t know what’s going to happen. I’ve tried to stop smoking and I can’t. I think if I enjoy a cigarette it’s me that’s taking the risk. Most of my family’s all smoked and none of them have ever died of cancer. I suppose if different family members died and it was through smoking, I may think different, but at the moment, no.” (D3–EU)

“Heart attacks run in the family and that’s pretty scary and I feel that’s a high risk . . . I’m just waiting for it to happen really . . . But I smoke, so . . . I’m doubting my risk. Don’t ask me why.” (F6–CU)

Discussion

Discussion of findings

The findings of this study provide useful information about women’s understanding of risk issues while making decisions about the menopause and HRT, and demonstrates an active risk assessment process involving the interplay between knowledge and core beliefs, with the weighing up of risks and benefits to facilitate an informed decision.

Risks were given meaning by placing knowledge, context and presentation against personal experience and core beliefs. The patient’s perspective thus varies markedly from the medical perspective which views risk in terms of numerical descriptions. Patients often thought the medical perspective was difficult to assess or trust, and some women found presentation of numerical risk more meaningful, while others gained more meaning from words. In an experimental setting Budescu et al. showed that some people prefer to receive risk information in numerical form, but prefer to express risk information using words: the primary care setting may differ markedly when people have to make decisions which relate to their own health and which may be personally threatening.

Patients wished to form their own opinion about the risk likelihood, supporting Calman and Royston’s suggestion that risk information needs to be developed which is presented in both words and numbers, and gives examples to add salience and context. The study shows that experiences of womanhood are central to understanding risk issues when considering the menopause and HRT, and it may be that risk information could capitalize upon this, by presenting contextual information relating to, for example, antenatal or oral contraceptive risks. Participants felt that generalized risk information was impersonal, and a more tailored approach may be possible with the use of CDSS’s: one-to-one risk communication would represent a more patient-centred approach, and may provide greater patient satisfaction.

The severity or ‘seriousness’ of risk issues was found to be salient as the personal threat of the likelihood of an adverse event seemed central to how most women made their HRT decisions, as they balanced risks and benefits, or the trade-off between ‘suffering’ and likelihood. There is little literature about risk seriousness, particularly in the clinical setting, and the extent to which perceptions of seriousness contribute to perceptions of risk remains unknown. Psychological theories provide some insights, such as the availability heuristic which suggests that risk perception depends upon the ease with which instances of the event come to mind, and Weinstein’s concept of ‘unrealistic optimism’, whereby people ignore their own risk-taking behaviour, and focus primarily on their risk-reducing behaviour. Such theories support the study findings by suggesting that perceptions of risk seriousness markedly affect the patient’s understanding of risk issues.

Family history had an interesting influence upon patient’s understanding of risk, as it provided not only risk knowledge, but also a wealth of lay beliefs. Women’s sense of personal risk of inherited diseases or tendencies was judged against that particular prevalence in their family (‘runs in my family’), and behaviour was often in response to this risk assessment. These findings are supported by socio-anthropological research, suggesting that beliefs about the inheritance of family characteristics include physical features and characteristics of behaviour and personality, as well as health and proneness to illness. The lay knowledge suggests that these characteristics are determined by what we inherit, with some contribution from the environment. A recent study on the lay constructions of a family history of heart disease,
suggests that the factors that patients and professionals judge as relevant to the confirmation of a family history can differ, leading to the potential for misunderstanding in the clinical encounter.22

Other personal beliefs were also salient, sophisticated and influenced interpretation of patient’s understanding of risk issues: they included beliefs about ‘womanhood’, fatalism, control and choice. Experiences of womanhood such as antenatal screening or the contraceptive pill often gave context to risk information: indeed, these events had often been a participant’s main risk information source prior to the menopause. Fatalism and the concept of control and choice were also prevalent. Fatalistic beliefs took the control of many risks away from people, and were at odds with the also frequently expressed need to exercise control over risk decisions. Ewald described risk as incorporating a ‘secularised approach’ to life which excludes spirituality,23 and it may be that ‘fatalism’ is simply an expression of the ‘secularised approach’, and a means of coping with hazards beyond their control. Lock suggests that risk assessment is like ‘reading the omens’,24 in seeking to avoid misfortune by risk management, new ambiguities and uncertainties are created. This increasing uncertainty surrounding risk decisions might explain the participants’ need for equipoise around the issues of fatalism and control.

The literature suggests that cognitive and mechanistic processes mainly determine risk communication and risk perceptions: the study suggests in addition that there is an important emotional, or non-cognitive, component. It may be that emotions produced by the synthesis of risk knowledge with core beliefs act as a ‘filter’ to prevent or deny further contamination of the core beliefs by risk information.

**Practice implications**

Utilization of these findings would help both patients and practitioners to recognize the complexity of lay and professional understanding of risk issues. Practitioners should ask patients about personal risk experiences and their beliefs as well as current symptoms.25 Risk communication may become more effective when it acknowledges the patient’s perspectives on ‘language’, framing and a personalized approach, as well as the effects of severity, lay beliefs and emotions caused by the risk under discussion. Assessing risk with benefit would have enabled these women to make ‘informed choices’ about the menopause and HRT. The quest for better informed choices is in keeping with recent trends towards improving patient choice in healthcare and HRT. The quest for better informed choices is in keeping with recent trends towards improving patient choice in health care26 and increasingly ‘truthful’ information. Furthermore, evidence suggests that increased levels of informed choice are associated with greater patient satisfaction with care and greater adherence to treatment options.27 Increased understanding of risk issues can therefore be expected to enhance patients’ informed choice and lead to an increase in ‘evidence-based patient choice’.28

**Limitations and future study**

In common with many qualitative studies, the sample was necessarily too small to generalize its findings with confidence, but it does include women of varying educational levels, parity, marital and occupational status from two practices in markedly contrasting areas. The main limitation of this study is that several of the groups were composed of women with varying HRT usage. However there was little variation in the themes that emerged from the mixed group discussions compared to the single HRT usage group discussions. The author’s presence at the groups may have influenced the participant’s readiness to talk, for instance the almost total lack of mention of sexual changes during the menopause could imply that the groups had reservations about discussing the breadth of relevant issues.

Further study will be valuable in continuing to explore the patient’s perspective, particularly the influence of their core beliefs and emotions upon the meaning of risk. Such work would be of value in other areas of risk management such as family history of cancer, diabetes and ischaemic heart disease, and antenatal screening.

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